

Review

A systematic review of depressive and anxiety symptoms in caregivers of dementia patients

Despoina Deli,¹ George Tsouvelas,² Dimitrios Roukas,³ Manolis Mentis⁴

¹Faculty of Medicine, University of Thessaly, Larisa,

²Department of Psychology, National and Kapodistrian University of Athens, Athens,

³Psychiatry Department, 417 NIMTS, Athens,

⁴Department of Educational Sciences and Social Work, University of Patras, Patra, Greece

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ABSTRACT

The current number of dementia cases in Europe stands at 7.7 million, a figure projected to double by 2050. Caregivers of individuals with dementia experience a heightened burden compared to those caring for other chronically ill individuals, increasing the risk of depression and stress disorders. This systematic literature review, following PRISMA guidelines, explores the prevalence of anxiety and depressive symptoms in dementia caregivers. Searches in academic databases, restricted to studies from the last 15 years, identified eighty-five articles with 16 meeting the inclusion criteria. Results indicate a significant caregiver burden, diminished self-reported quality of life, and a propensity for clinical depression. Depression and anxiety symptoms were more pronounced among female caregivers. Caregiver depression correlated with increased emergency department utilization by dementia patients, with a surge in depressive symptoms reported during the COVID-19 pandemic. Caregiving for dementia patients was associated with burnout, adversely impacting caregiver quality of life. Depression and anxiety symptoms in caregivers correlate with substance use. Sociodemographic variables, including low socioeconomic status, high urbanization levels, and older age, were associated with caregiver depression. Caregivers of individuals with Alzheimer's disease reported higher anxiety, burden, and depression scores compared to those assisting individuals with other dementias, particularly when neuropsychiatric symptoms were evident. The identification of the factors that are linked to the mental burden of caregivers allows mental health professionals to enhance symptom detection and provide tailored support, alleviating caregiver burden and improving dementia care quality. Systematic professional assistance and training opportunities through health policies can effectively alleviate caregiver burden.

KEYWORDS: Depression, anxiety, dementia, Alzheimer, caregivers.

Introduction

The current number of dementia cases in Europe is reported to be 7.7 million individuals, and projections suggest a twofold increase by the year 2050.¹ The Alzheimer's World Report 2015 indicates a global number of cases of 46.8 million individuals living with dementia in 2015, with a projected doubling approximate-

ly every two decades, reaching 74.7 million in 2030 and 131.5 million in 2050.² Regional variations are evident, notably in Japan where the aging population constituted 26.3% in 2015, surpassing rates in Western countries (19% in the European Union, 15% in the USA, and 8% worldwide).² This demographic shift signifies a considerable proportion of the elderly population, with estimates suggesting 1 in 4 individuals being elderly. Moreover,

the trajectory of population aging is anticipated to persist, with projections indicating that by 2060, 39.9% and 26.9% of the Japanese population will be aged over 65 and 75, respectively.³

The provision of care for dementia afflicted individuals places a considerable strain on familial caregivers, extending beyond the financial costs to include reduced productivity and significant emotional impacts. This caregiving responsibility has pervasive implications, which have an impact on psychological well-being and the overall quality of life and they also increase the susceptibility to psychopathological conditions, including anxiety and depression. Comparative studies indicate that family caregivers of dementia patients experience a greater burden than those caring for individuals with other chronic illnesses, leading to a higher risk of depression.⁴

Identifying factors that increase psychological distress among caregivers is essential, as their sustained well-being is crucial for delivering effective care to individuals with dementia.⁵ Research highlights several demographic determinants that heighten mental health challenges for caregivers, including lower educational attainment, limited income, being a spousal caregiver, female gender, and identifying as white.^{6–9}

Psychological and behavioral determinants, including a less favorable self-rated health, reduced social networks, use of dysfunctional (emotion-focused) coping mechanisms, and stress manifesting as role overload, restriction, or burden, have been identified as contributors to depressive symptoms.^{10–13} The burden indicators of the caregivers, are associated with the spectrum and intensity of the symptoms that are exhibited by elderly patients, including heightened behavioral issues, increased levels of physical disability [deficits in activities of daily living (ADL)], and diminished cognitive functioning, which have been documented as risk factors.^{6–7,14}

Material and Method

This review was conducted following the guidelines of the preferred reporting items for systematic reviews and meta-analysis (PRISMA). The purpose of the present study is to investigate the anxiety and depression experienced by caregivers of patients with dementia.

Search strategy

Systematic searches on computerized databases were performed, in order to retrieve English language material that has been published and developed over the last 15 years. The search was conducted through the elec-

tronic databases of academic research Google Scholar, PubMed and Scopus. The following combinations of words were set as criteria for the search: caregivers AND dementia; caregivers AND dementia AND depression; caregivers AND dementia AND anxiety.

Screening criteria

Inclusion criteria: (a) Study type: single quantitative study, qualitative analysis of interviews, systematic review, systematic review and meta-analysis, cohort randomized controlled trial (b) Population of study: caregivers of patients with dementia. (c) Outcome: affective symptom outcome (including but not limited to depression, anxiety, distress, etc.). Each study underwent a critical appraisal, initially assessing its title and subsequently scrutinizing its content. Studies deemed partially unrelated to the research subject were excluded during this phase. Subsequently, the remaining studies were further evaluated, and those lacking methodological rigor or exhibiting incomplete relevance to the research topic were excluded. This meticulous process culminated the compilation of the final list of studies included in the research.

Data extraction

Data from retained articles were manually extracted into a data extraction table using Microsoft Excel. Data extracted from the retained articles included: authors, title of the study, type of study, results (see table 1). The records screening process are shown through the flow-chart in figure 1.

Data synthesis and analysis

The diverse nature of the across studies data, in particular the methods of reporting symptoms or psychopathology, lead to an inability to construct a meta-analysis, therefore a narrative synthesis was used.

Results

A total of 85 records were retrieved from searching databases (Fig 1; Flow diagram of the search process). After removing twenty-three duplicates, 62 records were screened, of which 46 were excluded as not relevant. We included a total of sixteen studies, all of which were assessed for quality and included in the systematic review.

Characteristics of the studies meeting inclusion criteria are presented in table 1 and more detailed information regarding the characteristics of the studies can be found in table S1 in the appendix. Most studies were cross-sectional studies. Qualitative studies, systematic

Table 1. Data extracted from the retained articles.

S/N	Authors	Title of study	Type of study	Results
1	Ma et al 2018 ¹⁵	Alzheimer's' disease and caregiving: a meta-analytic review comparing the mental health of primary caregivers to controls	Systematic Review and Meta-Analysis	Caregivers of dementia patients have poor mental health compared to the general population, with female caregivers disproportionately affected.
2	Fong et al 2021 ¹⁶	Depression, anxiety and stress on caregivers of persons with dementia (CGPWD) in Hong Kong amid COVID-19 pandemic	Quantitative study-Cross-sectional design	High prevalence of symptoms of depression in caregivers of patients with dementia during the pandemic.
3	Alfakhri et al 2018 ¹⁷	Depression among caregivers of patients with dementia	Quantitative study-Cross-sectional design	Caregivers of patients with dementia experience significant psychological burden and lower health-related quality of life and are predisposed to develop clinical depression.
4	Guterman et al 2019 ¹⁸	Association between caregiver depression and emergency department use among patients with dementia	Longitudinal Cohort Randomized Controlled Trial	Dementia caregiver depression appears to be significantly associated with increased emergency department use by patients, revealing a key caregiver vulnerability that, if addressed with patient- and caregiver-centered dementia care, could improve health quality and reduce costs for this high-risk population.
5	Matsumoto et al 2007 ¹⁹	Caregiver burden associated with behavioral and psychological symptoms of dementia in elderly people in the local community	Quantitative study-Cross-sectional design	Certain symptoms such as hyperarousal, aggression, irritability and immobility in dementia patients can significantly affect the anxiety and depression symptoms of their caregivers, although their frequency and severity are low.
6	Huang et al 2012 ²⁰	Caregiver burden associated with behavioral and psychological symptoms of dementia (BPSD) in Taiwanese elderly	Quantitative study-Cross-sectional design	Patient delusions had the highest mean score on the caregiver distress scale, followed by agitation/aggression, anxiety, irritability/unsteadiness, and distress/depression. The frequency of symptoms of anxiety, delusions and agitation/aggression showed a statistically significant positive correlation with the score on the caregiver distress scale. Improving treatments for delusions, agitation/aggression, anxiety, irritability/instability, and distress/depression among dementia patients may reduce caregiver burden.
7	Mougias et al 2015 ²¹	The burden of caring for patients with dementia and its predictors	Quantitative study-Cross-sectional design	Younger caregiver age, high behavioral symptoms of dementia patients, and caregiver depression were found to be independently associated with caregiver burnout.
8	Alves et al 2019 ²²	Burnout syndrome in informal caregivers of older adults with dementia: A systematic review	Systematic Review	Burnout syndrome negatively affects the quality of life of caregivers and was associated with depression and anxiety symptoms and abusive behavior by the caregiver.
9	De Fazio et al 2015 ²³	Symptoms of depression in caregivers of patients with dementia: demographic variables and burden	Quantitative study-Cross-sectional design	The study confirms the presence of symptoms of depression in a large number of high-burden caregivers. However, it demonstrates that these symptoms are mainly associated with sociodemographic variables.
10	Del-Pino-Casado et al 2019 ²⁴	The association between subjective caregiver burden and symptoms of depression in caregivers of older relatives: A systematic review and meta-analysis	Systematic Review and Meta-Analysis	Caregiver burden is an important risk factor for developing symptoms of depression in elderly caregivers and may lead to clinical depression. Those who take care of people with dementia face a greater burden.

Continues

Table 1. Continued.

S/N	Authors	Title of study	Type of study	Results
11	Watson et al 2019 ²⁵	Depression and anxiety among partner and offspring caregivers of people with dementia: a systematic review	Systematic Review	Depression and anxiety symptoms were related to demographic factors, patient dementia characteristics, various caregiver psychological and social factors, and dyadic relationship factors. A number of important factors were consistently associated with symptoms of depression across studies. Female caregivers and adult-child caregivers, were more likely to experience such symptoms rather than husbands. It was also found that caregivers' coping strategies and activity limitation were strongly associated with symptoms of depression. The severity of dementia-related problematic behaviors was related to caregivers' symptoms of depression and anxiety. Additionally, significant factors associated with symptoms of depression were relationship type and quality of relationships.
12	Haley et al 2008 ²⁶	Long-term effects of bereavement and caregiver intervention on dementia caregiver symptoms of depression	Qualitative interview analysis by conducting repeat interviews	Patient death led to the diminishment of symptoms of depression for caregivers. The enhanced support intervention resulted in milder symptoms of depression both before and after bereavement.
13	Monteiro et al 2018 ²⁷	Coping strategies used by caregivers of people with Alzheimer disease: a systematic review	Systematic Review	The use and development of coping strategies reduces the effect of depression symptoms, anxiety and the burden of responsibility experienced by caregivers.
14	Sallim et al 2015 ²⁸	Prevalence of mental health disorders among caregivers of patients with Alzheimer disease	Systematic Review and Meta-Analysis	Caregivers of patients with Alzheimer have a higher prevalence of mental health disorders, particularly depression and anxiety, compared to the general population and their counterparts caring for patients with other diseases. The higher prevalence is mainly observed in female caregivers, caregivers with male care-recipients, and caregivers who have a spousal relationship with care-recipients.
15	Truzzi et al 2012 ²⁹	Burnout in familial caregivers of patients with dementia	Quantitative study-Cross-sectional design	42.1% of the sample, showed high levels of emotional exhaustion, and depersonalization was found in 22.8%. Depression was one of the most important predictors of their emotional exhaustion.
16	Valente et al 2011 ³⁰	Self-perception of health by dementia family caregivers: sociodemographic and clinical factors	Quantitative study-Cross-sectional design	The diminished perception of caregivers' health exhibited a correlation with elevated levels of emotional exhaustion, burden, as well as symptoms of depression and anxiety.

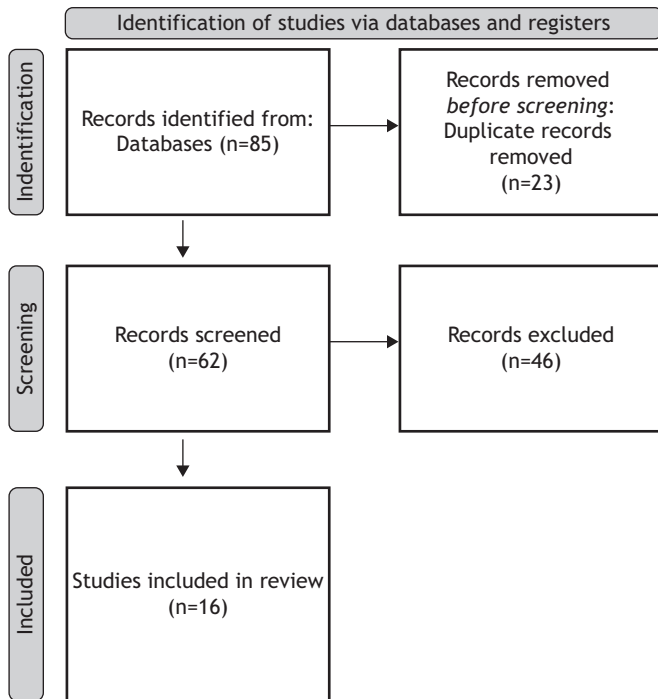


Figure 1. Prisma flow-chart of inclusion and exclusion of publications derived from the database searches.

reviews and meta-analyses were included in our study. Our systematic review of symptoms of depression and anxiety among caregivers of dementia patients reveals a concerning prevalence of psychological distress within this population. The findings consistently demonstrate that caregivers experience significantly higher rates of depression and anxiety compared to the general population, with female caregivers being disproportionately affected.^{15,28} The review identifies numerous factors contributing to caregiver distress. Notably, elevated levels of caregiver burden, associated with behavioral and psychological symptoms exhibited by dementia patients, are strongly linked to increased symptoms of depression and anxiety. For instance, caregivers managing behaviors such as aggression and irritability in patients report heightened anxiety and depressive symptoms.^{19–20} Our analysis also highlights the correlation between caregiver burnout and mental health outcomes. Younger caregivers and those dealing with significant behavioral issues in patients are at an increased risk for burnout, which in turn correlates with depressive symptoms.²¹ Furthermore, the presence of sociodemographic variables, such as caregiver age and relationship type, influences the severity of depression experienced.^{23,25} Coping strategies employed by caregivers emerge as a crucial factor in mitigating the effects of psychological distress. The effective use and development of coping mechanisms

can significantly reduce symptoms of depression and anxiety, emphasizing the need for targeted interventions that enhance caregiver resilience.²⁷ Overall, our review underscores the urgent need for comprehensive support systems for caregivers of dementia patients. By addressing the unique challenges faced by this demographic, we can improve their mental health outcomes and overall quality of life.^{18,22} Implementing patient- and caregiver-centered interventions can enhance the caregiving experience, reduce psychological burdens, and improve healthcare outcomes for this high-risk population.

Discussion

This study aimed to assess anxiety and depression levels among caregivers of individuals with dementia. To our knowledge, it is the first systematic review to apply the PRISMA methodology to explore these symptoms specifically in dementia caregivers.

Research findings indicate that caregivers of individuals with dementia encounter substantial burden and exhibit diminished health-related quality of life, with a notable susceptibility to clinical depression.¹⁷ Moreover, symptoms of depression and anxiety are discerned to be more pronounced among female caregivers, suggesting a disproportionate impact in comparison to their male counterparts.⁷ One possible explanation for the observed gender differences in caregiving may stem from stress-coping theory.³¹ Research suggests that women are more likely to employ maladaptive coping strategies, such as denial, escape, and avoidance, compared to men, who more frequently utilize effective strategies like problem-solving, acceptance, and distancing.³² Women may also experience caregiving in a more emotionally intense way than men, whose challenges may manifest differently, such as through poor health or disrupted sleep patterns. As a result, common assessment tools for measuring the negative aspects of caregiving may not fully capture men's experiences and could be more attuned to the challenges faced by female caregivers.³³

Additionally, the studies highlight a correlation between caregiver depression and heightened emergency department use for dementia patients.¹⁸ The ongoing COVID-19 pandemic is further identified as a contributing factor to an elevated prevalence of primarily symptoms of depression, along with other psychological effects, among caregivers of individuals with dementia.¹⁶

Several studies have illuminated the fact that the caregiver burden associated with the behavioral and psychological symptoms of dementia exhibits variability across different symptoms, indicating that the impact

does not uniformly correlate with the frequency and severity of the disease.²⁰ Specific symptoms such as agitation/aggression and irritability/immobility were identified in two studies as exerting significant effects on caregivers, notwithstanding their relatively low frequency and severity. Notably, in the context of Greece, caregiving practices diverge from those in other developed nations, with a predominant trend of familial care at home.²¹ This study revealed that nearly half of the caregivers displayed pronounced signs of mental fatigue, and almost a quarter of them experienced symptoms of depression. Factors such as the caregiver's early age, heightened behavioral symptoms in dementia patients, and caregiver depression were identified as independently associated with the manifestation of mental fatigue. The study underscores the complexity of mental fatigue, emphasizing its intricate interplay with various patient and caregiver factors, thus advocating for its incorporation into routine clinical assessments in dementia care practices.

Research consistently shows that caregiving roles can lead to burnout syndrome, negatively impacting caregivers' quality of life and correlating with depressive and anxiety symptoms in care recipients, as well as instances of abusive behavior by caregivers.²² Depression in caregivers is frequently linked to sociodemographic factors such as lower socioeconomic status, heightened urbanization, and advanced age. Additionally, a substantial body of research highlights a robust positive association between caregiver burden and symptoms of depression, with dementia caregivers exhibiting a higher effect size compared to those caring for frail elderly individuals and stroke survivors.²⁴ Converging evidence suggests that caregivers of individuals with Alzheimer's disease have to deal with elevated stress, burden, and depression, particularly in the presence of neuropsychiatric symptoms. Effective coping strategies can mitigate the impact of stressful situations, consequently improving caregivers' quality of life. Some studies suggest that enhanced supportive interventions were associated with reduced symptoms of depression in caregivers, implying that clinical strategies can potentially safeguard caregivers from chronic manifestations of depression. These findings underscore the need for new research focused on targeted interventions to address the complex challenges faced by caregivers.

Prevalence of mental health disorders within the caregiver population attending to individuals with Alzheimer's disease remains indeterminate. In a specific investigation, the aggregate prevalence rates were reported as follows: depression at 34.0%, anxiety at 43.6%,

and psychotropic medication use at 27.2%. This study discerned that the likelihood of experiencing depression was 1.53 times higher for female caregivers, 1.86 times higher for male caregivers, and 2.51 times higher for spousal caregivers.²⁸ Caregivers of Alzheimer's patients exhibited an elevated prevalence of mental health disorders, notably depression and anxiety, in contrast to both the general population and caregivers attending to individuals with diverse medical conditions.

In the broader context, the existing literature on the subject is limited, and lacks randomized controlled trials. Numerous contemporary clinical studies rely on cross-sectional research designs. Given the progressive deterioration of behavioral symptoms and daily life functions in dementia, there is a need for longitudinal studies with extended follow-up periods to ascertain whether caregivers' depressive symptoms undergo temporal changes.³⁴ The lack of standardized methodologies across studies has made it challenging to establish definitive indicators of psychopathology or related symptoms. Variability exists both in the methods used and, in the tools employed to assess depression and anxiety, while diverse data processing approaches further contribute to inconsistencies in reported outcomes across studies. Achieving greater consensus and uniformity in the scales employed for assessing these outcomes in future research endeavors would enhance the comprehension of the prevalence of anxiety, depression symptoms, or psychopathology in dementia caregivers. Consequently, the generation of more robust clinical evidence may necessitate an increase in high-quality randomized controlled trials with consistent methods for outcome evaluation. While evaluation criteria have been delineated, the potential for bias in results persists.

Considering the systematic literature review's findings, future research endeavors examining anxiety and depression in dementia caregivers should center on delineating the impact of specific behavioral and psychological symptoms of dementia, such as agitation/aggression and irritability/immobility. As suggested by Huang,³¹ comprehending the clinical mechanisms underpinning depression and anxiety necessitates an exploration of psychosocial, physiological, and biological factors. Furthermore, there is a need to investigate the role of the COVID-19 pandemic in amplifying the prevalence of depressive symptoms among dementia caregivers. Exploring interventions targeting the mitigation of burden and enhancing the health-related quality of life for caregivers, particularly those tending to Alzheimer's patients with neuropsychiatric symptoms, should be a priority in such research initiatives. Insights from such

research can inform the development of targeted support and interventions tailored to the unique challenges faced by dementia caregivers, leading to an improvement in their overall quality of life. The identified findings offer valuable insights for policymakers in shaping innovative programs and services aimed at alleviating and mitigating the strain experienced by caregivers, with consideration of diverse social and cultural contexts. A prevalent theme in the literature underscores

the imperative for additional research, a broader array of cultural approaches to caregiving.^{34–35} The formulation and execution of individualized treatment plans emerge as pivotal elements in addressing depression and anxiety among dementia caregivers. Advocating for increased attention, policy measures, and financial allocations is warranted to support forthcoming research endeavors focused on the multifaceted challenges faced by dementia caregivers.

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Ανασκόπηση

Συστηματική ανασκόπηση συμπτωμάτων κατάθλιψης και άγχους σε φροντιστές ασθενών με άνοια

Δέσποινα Ντελή,¹ Γιώργος Τσουβέλας,² Δημήτριος Ρούκας,³ Μανόλης Μέντης⁴

¹Τμήμα Ιατρικής, Πανεπιστήμιο Θεσσαλίας, Λάρισα,

²Τμήμα Ψυχολογίας, Εθνικό και Καποδιστριακό Πανεπιστήμιο Αθηνών, Αθήνα,

³Ψυχιατρικό Τμήμα, 417 ΝΙΜΤΣ, Αθήνα,

⁴Τμήμα Επιστημών της Εκπαίδευσης και Κοινωνικής Εργασίας, Πανεπιστημίου Πατρών, Πάτρα

ΙΣΤΟΡΙΚΟ ΑΡΘΡΟΥ: Παραλήφθηκε 19 Μαρτίου 2024/Αναθεωρήθηκε 29 Οκτωβρίου 2024/Δημοσιεύθηκε Διαδικτυακά 15 Δεκεμβρίου 2024

ΠΕΡΙΛΗΨΗ

Ο αριθμός των ατόμων με άνοια στην Ευρώπη είναι επί του παρόντος 7,7 εκατομμύρια και αναμένεται να διπλασιαστεί έως το έτος 2050. Οι φροντιστές ατόμων με άνοια αντιμετωπίζουν μεγαλύτερη επιβάρυνση από τους φροντιστές άλλων ατόμων με χρόνια ασθένεια και διατρέχουν μεγαλύτερο κίνδυνο να αναπτύξουν κατάθλιψη και διαταραχές άγχους. Μέσα από την παρούσα συστηματική βιβλιογραφική ανασκόπηση (PRISMA Analysis) επιχειρούμε να διερευνήσουμε τον επιπολασμό συμπτωμάτων και διαταραχών άγχους και κατάθλιψης σε φροντιστές ασθενών με άνοια. Πραγματοποιήθηκε μία αναζήτηση σε ακαδημαϊκές ηλεκτρονικές βάσεις δεδομένων με τον χρονικό περιορισμό οι μελέτες να έχουν δημοσιευτεί εντός των τελευταίων 15 ετών. Εντοπίστηκαν 85 άρθρα και συμπεριλήφθηκαν 16 τα οποία πληρούσαν τα κριτήρια. Τα αποτελέσματα των μελετών έδειξαν ότι οι φροντιστές βιώνουν σημαντική επιβάρυνση και μειωμένη αυτοαναφερόμενη ποιότητα ζωής, ενώ παράλληλα εμφανίζουν τάσεις για ανάπτυξη κλινικής κατάθλιψης. Τα συμπτώματα κατάθλιψης και άγχους βρέθηκαν να είναι πιο σοβαρά στις περιπτώσεις των γυναικών φροντιστών. Η κατάθλιψη των φροντιστών σχετίζεται με την αυξημένη χρήση του τμήματος επειγόντων περιστατικών από ασθενείς με άνοια και κατά την περίοδο της πανδημίας COVID-19 αποτυπώθηκε αύξηση του επιπολασμού καταθλιπτικών συμπτωμάτων σε φροντιστές ατόμων με άνοια. Η φροντίδα ατόμων με άνοια συνδέθηκε με την επαγγελματική εξουθένωση, επηρεάζοντας αρνητικά σε πολύ μεγάλο βαθμό την ποιότητα ζωής των φροντιστών. Αποτυπώθηκε συσχέτιση ανάμεσα στα συμπτώματα κατάθλιψης και άγχους των φροντιστών και την χρήση ουσιών από την πλευρά των φροντιστών. Η κατάθλιψη στους φροντιστές συσχετίστηκε με κοινωνικοδημογραφικές μεταβλητές όπως το χαμηλό κοινωνικοοικονομικό επίπεδο, το υψηλότερο επίπεδο αστικοποίησης και τη μεγαλύτερη ηλικία. Οι φροντιστές ατόμων με νόσο Alzheimer αναφέρουν σημαντικά υψηλότερες τιμές στα συμπτώματα άγχους, επιβάρυνσης και κατάθλιψης σε σύγκριση με φροντιστές που παρέχουν υπηρεσίες σε άτομα με άλλες άνοιες, ειδικά όταν τα νευροψυχιατρικά συμπτώματα είναι εμφανή. Με τον εντοπισμό παραγόντων που συνδέονται με την ψυχική επιβάρυνση των φροντιστών ατόμων με άνοια, οι επαγγελματίες ψυχικής υγείας θα έχουν τη δυνατότητα να προχωρούν σε έγκαιρη ανίχνευση συμπτωμάτων και να παρέχουν κατάλληλη υποστήριξη για να ανακουφίσουν το βάρος των φροντιστών και να ενισχύσουν την ποιότητα της φροντίδας για τα άτομα με άνοια. Μέσα από πολιτικές υγείας θα είναι χρήσιμο οι φροντιστές να λαμβάνουν περισσότερη και πιο συστηματική επαγγελματική βοήθεια και να έχουν ευκαιρίες κατάρτισης ώστε να μειωθεί η επιβάρυνση τους.

ΛΕΞΕΙΣ ΕΥΡΕΤΗΡΙΟΥ: Κατάθλιψη, άγχος, άνοια, alzheimer, φροντιστές.